



Improving the Health Status of Russian Women: A Participatory Research and Advocacy Project

AIDS Infoshare Russia

Massive transformations on the political, economic, and social fronts have characterized Russia in the past decade. At the same time, the country has been experiencing several new or intensified health crises: emerging epidemics of tuberculosis, HIV/AIDS, and other sexually transmitted diseases (STDs), as well as rising rates of alcoholism and drug abuse. Due in part to market reforms, government health care providers suffered a mass exodus of their work force. In the public sector, low and stagnant wages and the irregular payment of salaries have resulted in a medical establishment that is overextended and poorly staffed. A regular income can be secured in the private sector, where greater resources also mean better equipment and treatments.

In an effort to protect citizens' health rights in this period of dramatic change, legislation outlining the rights of patients and duties of health care providers and the state was passed in 1993.¹ However, research carried out in the mid-1990s by AIDS Infoshare Russia ("Infoshare"), in concert with nongovernmental organizations (NGOs) in 11 Russian cities revealed continuing violations of health-related rights, in contravention of established international human rights standards. That earlier project highlighted the need to train organizations to produce valid research to be used in improving the health status of Russians, especially women who are increasingly vulnerable to rights' violations. The project described in this brief was conducted from 1997-99. During the project period, Infoshare concentrated on action research and advocacy to promote and protect the health rights of Russian women through the simultaneous strengthening of the capacities of six Moscow-based women's organizations. Infoshare (*SPID infosvyaz'*) is a Russian NGO, which was founded to continue and enhance the work started by Infoshare International, a U.S.-based NGO founded in 1993 to provide Russians with information and tools to take actions against the spread of STDs and HIV/AIDS in Russia.

Objectives

The main objectives of this project were to:

- ▶ Provide the six partner organizations with training to protect their rights in the public health arena and to advocate for and work directly with their clients;
- ▶ Examine factors in Russian legislation and the existing health care system, which contribute to the health status of women;
- ▶ Generate widespread awareness of and discourse on the problems and research findings among policymakers and the media;
- ▶ Increase awareness among vulnerable groups of women about their rights within and outside of the health system and provide them with skills and tools to protect their rights.

¹ The *Fundamental Legislation of the Russian Federation on the Protection of Health of Citizens* (passed in July 1993) contains several specific articles designed to protect the health rights of citizens in the areas of consent, privacy, information, medical intervention, and other areas of medical ethics. This law places the responsibility and power to make decisions about medical/health treatment in the hands of the patient.

Methodology

Selection and Training of the Group

In the first phase, Infoshare sent questionnaires to women's organizations with which it had already worked, and whose clients are women who are among the most vulnerable to human rights violations and most hindered by the existing bureaucracy in the health system. The six organizations selected as local partners were:

- ▶ *Syostrii*—a center offering support to women who have experienced physical abuse;
- ▶ *Yaroslavna*—a center offering psychological support to young women;
- ▶ *Narcological Center*—a center offering support to drug users and medical treatment;

- ▶ *The Women's Information Link*—a community organization producing resource guides for women's organizations, working with elderly women;
- ▶ *Women's Unity and Collaboration*—a center working to protect the rights and interests of unemployed women;
- ▶ *Korolenko Institute of Venerology and Dermatology No. 14*—an institute attached to an STD clinic working with female commercial sex workers.

Once coordinators from each organization were chosen to be part of the monthly working group, Infoshare conducted three two-day training sessions led by a sociologist and a lawyer.

Data Collection and Dissemination

The next phase entailed the collection of data from clients of each of the working group members using in-depth interviews and twenty focus groups. The focus groups were divided into six categories: women of child-bearing age; women living with HIV/AIDS; elderly women; unemployed women; women drug users; and adolescent women.

After the data were collected, Infoshare held a two-day seminar, at which results were presented by each working group member. Infoshare staff led the compilation and analysis of the data to be used for dissemination in the last phase.

Results

Research Findings

The research showed that specific groups of Russian women faced a system that is insensitive to their needs and patients' rights:

- ▶ Women who are victims of abuse had few support groups and other essential services available to them;
- ▶ Women living with HIV/AIDS were most affected by the lack of confidentiality in health services;
- ▶ Elderly women living on state pensions and unemployed women could only access free services and generally were unable to pay for long-term private treatments;
- ▶ Women who use drugs generally visited a doctor only when

absolutely necessary. Health professionals often condemned them rather than trying to address the issues practically and without prejudice.

The feeling is like this: you're sitting alone in some public place, waiting in a queue, no one wants you there, you're no one's business, you're in everyone's way, and it would be better if you hadn't come.

— focus group participant

Common across groups was the finding that chronic understaffing and long waiting lines translated into "hurried" health care, exemplified by poor doctor-patient communications and a lack of patient access to quality information. Patients were

seldom informed about test procedures, results, treatments, and medicines and their side effects. The overwhelming majority of respondents doubted the extent to which the doctor respected the confidentiality of the patient despite legal provisions. Although many Russians have long distrusted the public health system and its doctors, recent economic problems have exacerbated their sense of dissatisfaction and frustration.

Training for Organizations and Vulnerable Groups

Although the working group was familiar with the concepts of social research, their experience was confined mainly to quantitative research and compiling statistics. Qualitative research was a new area

of study for all the organizations. Their knowledge of human rights law (both Russian and international) was comprehensive, yet there were gaps regarding how health-related legislation applied to individuals on a practical level.

The social science research training focused on methodologies for conducting research among vulnerable groups. The sessions on human rights covered topics such as a patient's right to receive modern medicines; the right to freedom from discrimination; the right to information; the right to agreement and refusal of method of treatment; and the right to doctor-patient confidentiality.² Participants attributed the frequent occurrence of violations of health-related rights to lack of knowledge about Russian legislation, lack of legal education for citizens and bureaucrats, and the absence of mechanisms in place for seeking redress.

The quintessential problem remains that women—particularly vulnerable women such as those living with HIV/AIDS, commercial sex workers, and women with drug dependencies—lack access to fundamental and vital information regarding human rights and personal health status. As a result of the training, information was made available through the existing structures of each of the women's groups.³ In addition, Infoshare convened ten two-day workshops for clients of each of the groups on the most common violations impacting the health status of women. The workshops also covered Russian legislation and specific statutes that regulate the doctor-patient relationship and legal

and social mechanisms for protecting one's rights.

Dissemination Activities

Infoshare convened a one-day conference to present the results of the project. Among the participants and guest speakers were members of Moscow's local authorities (representatives from the State Duma and the Russian Ministry of Health), the U.S. Agency for International Development (USAID) Mission in Moscow, the Canadian Embassy, the British Council, the Soros Fund, and the International Women's Club. A press conference for members of the Russian and international press spotlighted the results of the project for policymakers. As a follow-up, an "open letter" calling for the improvement of women's health status was sent to the Moscow government to ensure that conference issues remained in the forefront of debate within governing bodies. All project reports and materials, including conference proceedings, will be translated into English to raise awareness within the international community.

Private funding was obtained for six 30-minute programs on a national radio station, in which each member of the working group discussed particular discrimination and human rights violations women face in the health system, and organizations to whom they can turn for assistance.

Infoshare compiled information for all vulnerable groups into one brochure: "My Rights in the Health System." Five thousand copies have been distributed throughout the medical establishment in Moscow (AIDS centers, dispensaries, and STD clinics),

through other women's organizations, and by the working group to their specific client groups. This brochure includes information on:

- ▶ Basic legislation on civil public health rights and the Hippocratic Oath;
- ▶ Existing system of public health (including the different obligations of specialists);
- ▶ Existing insurance system;
- ▶ Case studies of human rights violations and recommendations made by a lawyer on what could be done in each situation;
- ▶ Referral addresses to organizations that can help with specific problems.

Another brochure, "Only For You," provides information on the best, most accessible STD services in Moscow and is being distributed among STD clinics and via regular weekly outreach work on Moscow streets.

Conclusions

A more sophisticated understanding of the link between the protection and promotion of human rights and the health of individuals and communities is now beginning to emerge, supported by research around the world. The research and advocacy conducted through this project contributes to that growing body of data. Infoshare helped open discussion on existing Russian legislation on the health care system (i.e., how it protects or violates women's human rights). It was especially useful that the discussion occurred at many levels: among patients using the services, among NGOs, and at the official Ministerial level.

²With the exception of the right to receive modern medicines (due to current economic restrictions), participants widely agreed that these rights are realizable within the Russian context.

³For instance, Syostrii advertised an additional service on their hotline to provide women with consultations on their rights in the health care system; the Women's Information Link published the research findings in their resource guide; and Women's Unity and Collaboration incorporated the findings into their consultations with unemployed women.

Recommendations and Lessons Learned

The following recommendations for further health policy analysis and reform in Russia emerged from project research and advocacy:

► **Conduct analysis on the organization and staffing of public health care services.**

Individual medical staff members plan their work schedules, cope with the problems of understaffing, as well as provide treatment and care to patients. This accounts for the enormous variation in care. It was apparent through Infoshare's research that the management, monitoring, and evaluation of services by a larger government health office was virtually nonexistent and must be rectified in order to improve overall service delivery.

► **Conduct analysis on the equity and accessibility of medical services.**

It is not clear to what extent individuals are prevented from accessing health services for financial or logistical reasons, or for lack of registration as Moscow residents.⁴ Part of the solution involves broadening the focus of government health care resources beyond Moscow to implement programs to improve health services in rural areas.

► **Reform policies to encourage voluntary health-seeking behaviors.** Public policy should encourage vulnerable populations like female commercial sex workers or drug users to seek assistance in protecting their health. Advocacy activities should make it clear that the criminalization of these acts prevents these individuals from accessing health care services, by fostering fear of arrest and social marginalization. NGOs should concentrate on providing information on behavioral risk-reduction and encouraging health-seeking behaviors. This is especially urgent considering the alarming increase of HIV among intravenous drug users.

The following lessons came out of the project's experiences in Russia but are applicable to many nascent democracies:

► **Strengthening the internal structures of emerging women's groups is a priority.** Infoshare found that although the working group did not always run smoothly, this very process provided invaluable lessons and skills for those six partner organizations in negotiating and collaborating on projects. Women's NGOs such as these are relatively

young, lacking both essential organizational skills and concrete work experience. They need further training in proposal writing, organizational management, the legislative process, and in collaborating with the media (e.g., in producing informational brochures and organizing seminars and press conferences). This capacity building is essential if these NGOs are to be seen as a legitimate lobbying force able to shape public policy.

► **Collaborative research undertaken by academic institutions and NGOs has clout.**

Infoshare conducted joint research with a sociologist from the Moscow State University Institute of Sociology on qualitative data collection and analysis of results. Since the research was conducted using valid sociological methods and was administered by a professional affiliated with an academic institution, it was far more influential with policymakers than if it had been submitted by a group of NGOs alone. The NGO sector is still a relatively new phenomenon in countries like Russia, whereas academic institutions (although poorly funded) are widely respected.

⁴ In order to receive subsidized health services within Moscow, patients must be registered as residents of the city/province. The difficulties arising from economic restructuring have led to an influx of people from other Russian provinces into the Moscow area in search of work. Many of these approximately 3 million newcomers, especially women, have not formally registered as residents.

International Center for Research on Women
1717 Massachusetts Avenue, NW, Suite 302
Washington, DC 20036, USA
Tel: (202) 797-0007; Fax: (202) 797-0020
www.icrw.org

The Centre for Development and Population Activities
1400 16th St., NW
Washington, DC 20036, USA
Tel: (202) 667-1142; Fax: (202) 332-4496
www.cedpa.org

Information for this brief was taken from:

AIDS Infoshare Russia. 1999. "Improving the Health Status of Russian Women: A Participatory Research and Advocacy Project." Final technical report for PROWID to the International Center for Research on Women.

For additional information and project-related documents, please contact:

Ms. Julie Stachowiak at jstachow@jhsph.edu or
Alena Pyoroshina, AIDS Infoshare
P.O. Box 51
Moscow 105037, Russia
Tel/Fax: 7 095 383 7553; Email: infoshare@glas.apc.org

The publication of this report is made possible through the Promoting Women in Development (PROWID) program, funded by the Office of Women in Development at the United States Agency for International Development (USAID) under the terms of Cooperative Agreement No. FAO-A-00-95-00030-00. The opinions expressed herein do not necessarily reflect the views of USAID, ICRW, or CEDPA.

Copyright© 1999 International Center for Research on Women and The Centre for Development and Population Activities